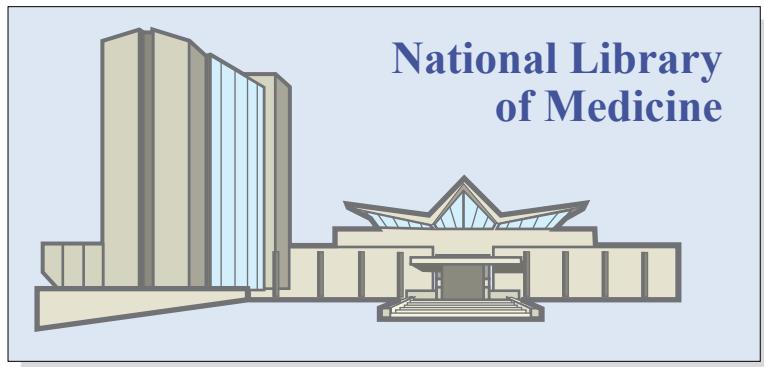


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**Understanding
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November 2003

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Understanding Health Literacy and its Barriers

January 1998 through November 2003, plus selected earlier and later citations

651 Citations

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2004 May

**US DEPARTMENT OF HEALTH
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INTRODUCTION

What is health literacy? The current operational definition used in *Healthy People 2010* is: "the degree to which individuals have the capacity to obtain, process and understand basic health information and services for appropriate health decisions."¹ Health literacy is the means by which holders of knowledge can make that knowledge understandable and usable for the receiver.

In the five years since the National Library of Medicine released the first *Current Bibliographies in Medicine* (CBM) on this topic², national interest in health literacy has increased. A growing number of disciplines are contributing new knowledge about the implications of literacy challenges and the disproportionate impact of those challenges on some groups and populations. So much had been added to the literature, it was clear the time had come for another bibliography.

At the core of this accelerated interest is the growing realization that more than 90 million Americans struggle to understand basic health information.³ For example, one research study in a public hospital found that one-third of English-speaking patients could not read basic health materials. More than a quarter could not read appointment slips and forty-two percent did not understand labels on prescription bottles.⁴ The 2000 census counted 20 million people who speak poor English, 10 million who speak no English. The White House Office of Management and Budget in a 2002 report estimated the number of patient encounters across language barriers each year at 66 million.⁵

Ascertaining public need, using appropriate communication strategies and tactics, ensuring access and usability, identifying and removing obstacles within systems, and continuously evaluating the efforts to ensure improvement, are all competencies required to achieve health literacy. The Institute of Medicine of the National Academy of Sciences emphasizes the significance of these competencies saying, "Health literacy is where the expectations, preferences and skills of individuals seeking health information meet the expectations, preferences and skills of individuals providing information. Health literacy arises from a convergence of education, health services, and social and cultural factors, and brings together research and practice from diverse fields."⁶

Low or limited health literacy might best be described as a weakness in connecting—or a complete failure to connect—the audience with appropriate health information materials, services, or resources. Addressing this chasm of communication, Federal public health leaders, including the Secretary of the US Department of Health and Human Services and the Surgeon General of the United States, are currently calling for national action on health literacy. The Secretary emphasized, "The health of our country depends on our understanding of basic health information in order to lead a healthy life."⁷ Echoing the same theme, the Surgeon General highlighted health literacy needs and proposed specific steps to capitalize on the Healthy People 2010 initiative on health literacy. He noted, "The ability to access, understand, and use health-related information and services is critical to the success of my three priorities: improving emergency preparedness, and eliminating health disparities, and preventing disease."⁸

Resources for these three foci are within this bibliography. Candidate citations were identified primarily by searching online databases and the Internet. We selected only English language material and generally excluded letters, editorials, or literature published before 1998, unless they provide an important historical context. The selected citations are from a variety of disciplines to highlight resources available to medical, health, education, and communication professionals as they tackle this important national challenge. Primarily, this bibliography includes citations from literacy literature only when in a health literacy context. In this context, selections are from health education, communication (interpersonal, institutional, systems, interactive, listening, accessibility), risk, compliance, informed consent, professional-patient interaction, cultural competence, and health disparities research.

Selections are also included from literature on reading, numeracy, contextualization, visual and auditory comprehension, accessibility, translation and interpreter use, the navigation of medical systems by individuals with cultural differences or literacy challenges, materials development or materials evaluation

for various cultural groups or those with varying health literacy challenges, and mental health literacy. The Web sites were selected using the National Cancer Institute evaluation criteria for content⁹ and usability.¹⁰

We urge the reader to keep two caveats in mind when utilizing this bibliography. First, within it are many attempts to quantify health literacy by sets of skills or attributes in an effort to find a universal formula or "recipe" for a more universal solution to the problem of low health literacy. These attempts to find a universal solution may seem straightforward until the standards are applied to real circumstances. For example, there is a major difference between "a sixth grade reading level" applied to an actual sixth grade child who has limited life experience and "a sixth grade reading level" used as a measure of vocabulary and comprehension skill of an adult who has much more life experience upon which to draw. Secondly, within the bibliography are articles describing differing approaches to evaluation of specific materials in specific settings with specific audiences that may or may not have implications for other materials, settings, or audiences.

This bibliography is meant to complement the *Health Literacy* CBM done earlier. Whereas that bibliography sought to define the problem and examine potential strategies, this one examines some of the barriers that may need to be addressed when designing such strategies. We hope that it will stimulate additional interest in research related to health literacy. We also hope that an increase in research and a broader understanding of research results will provide a foundation for disease prevention and health promotion for the 90 million Americans who struggle with challenges of literacy each day.

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SAMPLE CITATIONS

Citations are formatted according to the rules established for *Index Medicus®**. Sample journal, monograph, and Web site citations appear below.

Note also for journal articles than an availability statement follows many citations. This statement contains the identification number (PMID) for the citation in the NLM PubMed retrieval system. The user may enter this number in PubMed on the NLM Web site (<http://pubmed.gov>) to retrieve the record, which includes an abstract for most articles and may also provide a link to the publisher's Internet site.

Journal Article:

Roter DL, Rudd RE, Comings J. Patient literacy. A barrier to quality of care. *J Gen Intern Med*. 1998 Dec;13(12):850-1. Available from PubMed; PMID 9844085

Order, with separating punctuation:

Author 1, Author 2, Author 3. Article Title. Abbreviated Journal Title. Date;Volume(Issue):Pages.
Availability.

Monograph:

Thompson TL, Dorsey AM, Miller KI, Parrott R, editors. *Handbook of health communication*. Mahwah (NJ): Lawrence Erlbaum Associates; 2003. 753 p.

Order, with separating punctuation:

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Web Site:

Health Literacy [Internet]. Mount Pleasant (MI): Michigan Adult Learning & Technology Center; [modified 2003 Apr 16; cited 2004 Apr 30]. Available from: <http://www.malt.cmich.edu/healthlit.htm>

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